

Marie Curie submission of 11 September 2023

PE1956/G: Increase the provision of wheelchair accessible homes

Key issues

- Home environment plays a crucial part in enabling terminally ill people to be cared for at home, and to die there if that is their wish.
- Existing housing stock is often unsuitable for supporting terminally ill people's needs at home, and they experience significant barriers, delays and costs for housing maintenance and adaptations which they cannot afford. This is particularly acute for people living with multi-morbidities whose needs vary and are often complex, as well as for their families and carers.
- By 2040, up to 10,000 more people will be dying with palliative care needs, and two thirds of all deaths will take place in community settings; in people's own homes, care homes and hospices.

What needs to happen?

1. Scottish Government to take an equity-informed approach to its new Housing Standard and Scottish Accessible Homes Standard to reflect the needs of terminally ill people living with multi-morbidities for both existing and new home, with a single definition of 'accessible homes', co-produced with people with lived experience of dying, death and bereavement, Local Authorities and Housing Providers.
2. Scottish Government to provide ringfenced funding for social housing and local government to support building more accessible homes.
3. Health Boards must improve data capture to include terminally ill people using medical equipment to better inform place-based approaches to community support needs.

- 4. Local authorities to use BASRiS forms to fast-track housing maintenance, adaptations, and moving requests for terminally ill people, their families and carers.**
- 5. Scottish Government to provide greater financial support for people affected by dying, death and bereavement, to support increased costs brought on by terminal illness.**

The cost of dying

A UK Research and Innovation (UKRI) funded study called Dying in the Margins, undertaken by University of Glasgow and Marie Curie, examines barriers to, and experiences of, dying at home for terminally ill people, their families and carers living with financial hardship and deprivation through photography and digital storytelling.

Key findings to date relevant to the committee are around existing housing stock often being unsuitable for supporting terminally ill people's needs at home, and they experience significant barriers, delays and costs for housing maintenance and adaptations which they cannot afford.

This is particularly acute for people living with multi-morbidities whose needs vary and are often complex, as well as for their families and carers.

This is Linda's story, told by her daughter Nicola from the Dying in the Margins study:

My mum lived on the fourteenth floor of a tower block. The lift only went to the thirteenth floor. Moving back home with all the equipment she would have needed would have been practically impossible. The space would have been too small for me, my mum and three children and we couldn't afford childcare to allow me to focus on caring for her.

In the end, she was transferred to a hospice ten days before she died. The hospice was brilliant, and I'm so glad she didn't die in hospital, but I know she would have wanted to be at home. I just couldn't do that for her with what we were offered.

This highlights the unsuitability of current housing stock for terminally ill people and its impact on multiple aspects of end of life experience. As a result of this, Linda did not have the death she wanted- to die at home.

Fast and suitable adaptations:

While building more accessible homes would be welcome and is necessary, the first preference of many terminally ill people living in unsuitable accommodation is that their current home is adapted to suit their needs to enable them to die there if that is their wish.

Marie Curie Nurses and Healthcare Assistants across Scotland reported to our internal 2021 survey that they regularly visited terminally ill people who use a wheelchair, but living in homes with doors too small for them to fit through. Every effort must be made to ensure people can stay in their own homes, with adaptations, at the end of life if that is their wish:

“A man who is an amputee was told by an OT that he would be unable to get adaptations to his home in the first instance so should be putting his name onto the housing list for sheltered accommodation. Whilst this was happening he had then gone back into hospital.”.

Marie Curie Healthcare Assistant, Fife.

Long waiting periods for adaptations are also common for people living with terminal illness. This has been exposed by MND Scotland in their “No Time to Lose” report which found people with an MND diagnosis waiting over a year for the installation of ramps and wet rooms. Motor Neurone Disease, and other terminal conditions, can be unpredictable and mean patients can deteriorate rapidly.

Local Authorities must work more proactively by adding terminally ill people to waiting lists for accessible homes as soon as they receive their diagnosis.

We believe they can do this by identifying people who have a terminal illness through use of BASRiS forms. These forms replaced DS1500 forms in Scotland and are used to allow people to be fast-tracked when applying for specific social security benefits, including Adult Disability Payment.

Some local authorities already use BASRiS forms to fast-track adaptation requests from terminally ill people and this should be the standard process across Scotland.

Cost is another factor preventing people from having the necessary adaptations in place. Marie Curie and Loughborough University research has found that over 8,200 people die in poverty at the end of life every year in Scotland.

This equates to one in four working age people, and one in eight pensioners.

The double burden of income loss and increased costs brought on by terminal illness, including home adaptations and higher energy bills, mean people are being forced below the poverty line. A 2023 Marie Curie study has estimated that working age people in the UK can face a 75% rise in their energy bills after a terminal diagnosis and having to give up their job at the same time.

This also applies to carers, and can have a cumulative effect that means even subsidised adaptations through Local Authorities' scheme of assistance, designed to provide grants to help with excess costs, are too costly at the end of life.